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MATERNAL EXPERIENCE IN THE DIAGNOSTIC ITINERARY OF CHILD CANCER

EXPERIÊNCIA MATERNA NO ITINERÁRIO DIAGNÓSTICO DO CÂNCER INFANTIL

LA EXPERIENCIA MATERNA EN EL ITINERARIO DIAGNÓSTICO DEL CÁNCER INFANTIL

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ABSTRACT

Objective: to understand the experience of maternal disease and narrative in the diagnostic itinerary of childhood cancer. ***Method:*** qualitative research conducted through an interview with 18 mothers who attended the Chemotherapy Outpatient Clinic in a public university hospital in 2011, based on the guiding question: *Tell me how the health professional communicated the news about your child's illness and describe your perceptions at that time*. ***Results:*** to confirm the diagnosis of cancer, the mothers sought, on average, 3.3 health services. From the analysis of the speeches, two categories resulted: The path: from the first signs and symptoms until the diagnosis; the feelings revealed after the diagnosis of cancer. ***Conclusion:*** gaps were detected in the health service regarding the early identification of cancer and a world of suffering and uncertainty in the path traveled until the diagnosis, which in turn revealed feelings such as fear of death and insecurity, but also the hope of a cure. ***Descriptors*:** Neoplasms; Child Care; Delivery of Health Care; Pediatric Nursing; Oncology Nursing.

RESUMO

Objetivo*:** apreender a experiência de doença e narrativa materna no itinerário diagnóstico do câncer infantil. ***Método*:** investigação qualitativa realizada por meio de entrevista com 18 mães que frequentavam o Ambulatório de Quimioterapia em um hospital universitário público, em 2011, partindo da questão norteadora: *Conte-me como o profissional da saúde transmitiu a notícia sobre a doença do seu filho e descreva suas percepções naquele momento*. ***Resultados*:** para a confirmação do diagnóstico de câncer, as mães buscaram, em média, 3,3 serviços de saúde. Da análise dos discursos, resultaram duas categorias: *O percurso: dos primeiros sinais e sintomas ao diagnóstico*; *Os sentimentos revelados frente ao diagnóstico de câncer*. ***Conclusão*:** detectaram-se lacunas no serviço de saúde quanto à identificação precoce do câncer e um mundo de sofrimento e incerteza no trajeto percorrido até o diagnóstico que, por sua vez, revelou sentimentos como medo da morte e insegurança, mas, também, esperança da cura. ***Descritores: Neoplasias; Cuidado da Criança; Assistência à Saúde; Enfermagem Pediátrica; Enfermagem Oncológica.

RESUMEN

Objetivo: captar la experiencia de la enfermedad y la narrativa materna en el itinerario diagnostico del cáncer infantil. ***Método:*** investigación cualitativa realizada a través de entrevista con 18 madres que asistieron al Ambulatorio de Quimioterapia en un hospital universitario público, en 2011, partiendo de la cuestión guía: *Dime cómo el profesional de salud transmitió la noticia sobre la enfermedad de su hijo y describa sus percepciones en el momento*. ***Resultados:*** para la confirmación del diagnóstico de cáncer, las madres buscaron, en promedio, 3,3 servicios de salud. El análisis de los discursos, resultó dos categorías: *La ruta: dos primeros señales y síntomas al diagnóstico; Los sentimientos revelados ante al diagnóstico de cáncer*. ***Conclusión:*** se detectaron brechas en el servicio de salud con respecto a la identificación temprana de cáncer y un mundo de sufrimiento y la incertidumbre en el camino recorrido hasta el diagnóstico, que a su vez, reveló sus sentimientos como el miedo a la muerte y la inseguridad, pero, también, esperanza de cura. ***Descriptores*:** Neoplasias; Cuidado del Niño; Prestación de Atención de Salud; Enfermería Pediátrica; Enfermería Oncológica.

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INTRODUCTION

O Childhood and juvenile cancer, which ranges from zero to 19 years, accounts for 2% to 3% of all malignancies. In Brazil, with the exception of non-melanoma skin tumors, an estimated 11,530 new cases of cancer in children and adolescents were estimated for 2013, out of a total estimated 384,340 cases.[1]

Leukemia is the most frequent type in this age group, accounting for between 25% and 35% of all types, with Acute Lymphoid Leukemia (ALL) being the most frequent in the world. In developed countries, pediatric cancer is the second cause of death between zero and 14 years, followed only by accidents.[2] At these sites, lymphomas rank third among the most common, while in developing countries they appear second place. Central nervous system (CNS) tumors represent around 8% to 15% of pediatric tumors globally, and solid tumors are the most frequent.[2]

A review of the literature in 2011 points out that in the juvenile stage, tumors are generally not related to carcinogenic factors and are more aggressive, compared to cases involving adults4. However, the early detection of signs and symptoms favors timely treatment, increasing the life expectancy of this age group.[2-3]

Studies indicate that the diagnosis of cancer is more difficult during childhood and the delay can be attributed to factors related to the child, his parents and the health service or to diseases peculiar to this age group. In relation to the child or the disease, these factors are related to the type and location of the tumor, the age of the child, clinical suspicion, stage of the disease, perception of the disease and parental level of education, distance from treatment centers and health care system, plus fear or unpreparedness for early detection.[3-5]

Diagnostic confirmation commonly results in family imbalance, and stigma confronts with the disease, which becomes an imminent threat and arouses the inability to pronounce the word "cancer" or "death" because it is believed to be incurable.[6-7]

In view of this scenario and the successive approximations with families in a reference outpatient clinic for the diagnosis and treatment of childhood and juvenile cancer, the need to apprehend the experience of maternal disease and narrative in the diagnostic itinerary of childhood cancer became evident. This has been one of the most important themes in the socio-anthropological studies of health, regarding the concept of experience of the disease. After all, when one becomes ill, there is the involvement of the individuals that make up that person's circle of relationships, and together, with their beliefs, they devise strategies to overcome this event in a frantic search for the resolution of the problem that, to disrupt the family nucleus.[8]

The importance of this theme for Nursing is based on the intrinsic association with care, whether as a profession, discipline or work. In addition to this attribute, research and management practices, with production and mastery of knowledge, enable professionals to provide assistance during all stages of life. Both work and care in Nursing involve *"[...] an interpersonal meeting with therapeutic purpose, comfort, healing when possible and also preparation for death when unavoidable."* [9: 10]

As the health professional understands the experience of the illness both in the individual and in the community, it potentiates the practice of full and shared care, considering the peculiarities of the biopsychosocial and cultural needs of the child and / or adolescent with cancer and their families.

OBJECTIVE

- To learn the experience of maternal disease and narrative in the diagnostic itinerary of childhood cancer.

MÉTHOD

Article extracted from the research project entitled "Perceptions of the family of children with cancer on diagnosis communication", Department of Nursing, Health Sciences Center, Londrina State University (UEL), Londrina (PR), Brazil.

A descriptive study, using a qualitative approach, using the theoretical reference, the experience of illness and narrative, understood as a subjective experience, and constitutes a reality endowed with a socially recognized and legitimized meaning.[8]

The study was carried out from the survey of the cases of children with cancer in the Chemotherapy Outpatient Clinic (COC) of a public university hospital in the north of Paraná, Brazil. The subjects of the investigation consisted of 18 mothers of children in cancer treatment who attended for consultation in the COC from September to November 2011.

This outpatient clinic, which serves children and adult oncologists in the different specialties (general oncology, hematology and pediatric oncology), has a multidisciplinary

health team composed of nurses, physicians, psychologists, nursing technicians / assistants and social worker. Residents of Medicine and Nursing.

In order to preserve the identity of the research subjects, we opted for the use of codenames, so that the child's name was replaced by the name of a flower, preceded by the words "mother of".

The data were produced in one of the offices available in the COC, using a form with closed and open questions. The closed questions, filled by the researcher, dealt with the maternal-family, socioeconomic and demographic characterization. The responses were recorded from the following guiding question: Tell me how the health professional conveyed the news about your child's illness and describe your perceptions at that time.

For the analysis of the data, regarding the sociodemographic family maternal characterization, numerical treatment was carried out and, with regard to the open question, the transcription was carried out in full with subsequent follow-up of the steps of preanalysis, material exploration and treatment results. After reading, we selected the broader categories identified in the speech that corresponded to the study objective. The selection of contents emerged through a process of comparison, grouping the units of meaning by similarities and differences that generated the categories of analysis.[10] In the presentation of the speeches, grammatical corrections were made and expressions and language vices were removed that did not make sense to the text.

The research project was approved by the Committee of Ethics in Research involving Human Subjects of the State University of Londrina (CEP / UEL), under the opinion no. 134/2011, CAAE No. 0085.0.268.000-11.

RESULTS

The study included 18 mothers whose mean age was 32.2 years, with a predominance of married women (n = 13) and an average of 1.8 children per woman. As for the level of schooling, nine had primary education; seven, high school and two, the higher education.

In relation to professional activity, 14 were autonomous. The family income ranged from one to 13 minimum wages, in force in the year of collection, eight of which had income of one to two wages; three, two to three salaries and seven to three or more. In relation to the government grant, eight were contemplated.

Regarding the diagnosis of the children who were being followed up in COC, ten were due to acute lymphoid leukemia (ALL) and eight to other types of tumors.

As for the speeches of the mothers seized in the interviews, the itinerary that the families went through in the health services, from the first signs and symptoms to the diagnosis of cancer, was extracted. The average number of health services sought in this period was 3.33. Figure 1 below shows the genogram and ecomap of one of the families representing the others. In the ecomap, family members are in the center of the median circle (A), while the contacts with the community or with significant people and groups are represented in the others (B). Each line model corresponds to a type of connection, the arrows signifying energy and flow of resources, the solid lines are strong links, the dotted lines denote fragile connections and the absence of lines indicates a lack of connection.11 Note that the itinerary of this family has developed without adequate support, since there are weak connections with the services available in the city where they lived and there is no relation with the other members. Diagnostic confirmation occurred after traveling through the three levels of health care and four different locations, having, in the last hospital, access to the most diverse services and resources.

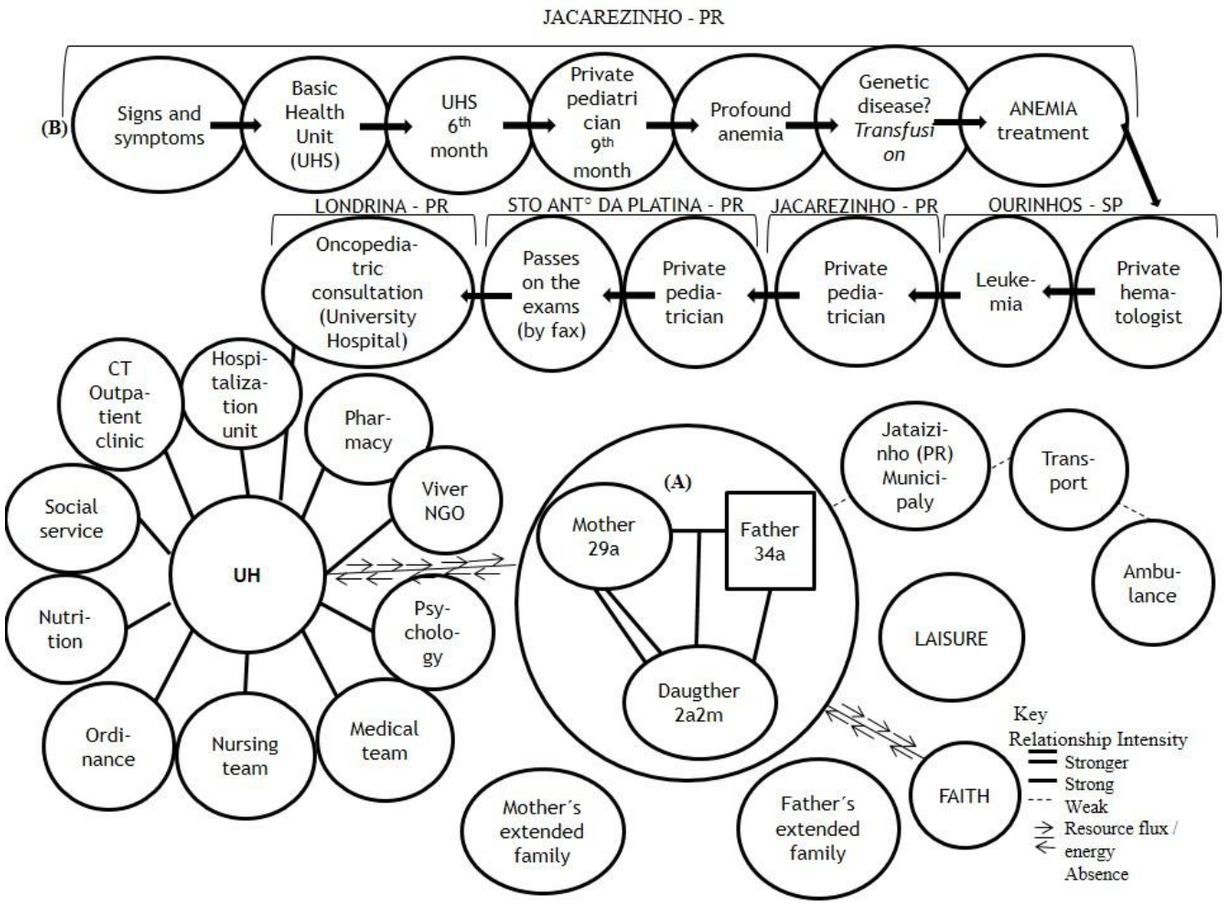

Figure 1. Graphical representation of the diagnostic route, genogram and ecomap of the Girassol family. Londrina (PR), Brazil, 2015.

Regarding the discourses of the mothers of children with cancer, after the analysis, perceptions and feelings emerged that made it possible to construct two categories: 1. The path: from the first signs and symptoms to the diagnosis and, 2. The feelings revealed in the diagnosis of cancer.

♦ The course: from the first signs and symptoms to the diagnosis

This subtopic encompasses the maternal reports regarding the physical and behavioral changes presented by the children that resulted in the search for some health service in order to identify the problem. After this attitude, the journey started by the family begins to obtain diagnostic confirmation and initiation of treatment.

In the speeches to follow, some mothers affirm that, from the beginning of the illness of the child, they realized that their children did not present common signs and symptoms. Other reports indicate that when it was not them who identified such signs and symptoms, one family member reported that something different was happening to the child. They also mention the signs and symptoms observed, similar to leukemia, as well as to other types of cancer, such as tumors and ganglionary:

> *She was six months old at the time when she found out, she was already nine inches already, it was in the abdomen [...] But we saw that she was so white. From time to time she would get a fever, and I would bring her to the doctor, but, ah, normal, she said it was a virus. [...] hence that's what happened, she had the first surgery (Mother of Dahlia);*
>
> *[...] She had (diarrhea) too, just like that, her belly. Only thin, arms, legs and just a growing belly. [...] she could not eat. [...] As soon as she started walking, I already saw that she was different [...] (Mother of Hibiscus);*
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> *Margarida had an absurd bone pain, that she could not take a shower that it hurt, she could not get out in the wind that hurt ... she is all purple, swollen in her joints, fingers, legs, feet (Mother of Margarida).*

Although most mothers and relatives identified signs and symptoms of worsening child health, there were those who did not know or did not know what was happening to their child:

> *But then she (the child) got the flu and got a little cough, then I took her to the doctor, then he prescribed me an inhalation, a syringe for me to drip in her nose and (pause) a remedy for fever that is a Paracetamol and for cough that is an amoxicillin, which they always prescribe there for coughing (Mother of Iris);*
>
> *[...] then I told my husband: "I think I'm going to take him to the doctor, I think he has anemia" (Mother of Tulipa);*

[...] Then I talked to the Doctor, "crazy," if it is tuberculosis, I also have tuberculosis, because I was coughing, coughing, coughing. Then they left us waiting for a few more days, I was hospitalized, because they thought I had tuberculosis and I passed it to her (Mother of Hydrangea).

At the beginning of the child's illness, the parents sought, firstly, the primary care services, the Basic Health Units (BHU) and 24-hour or outpatient units for consultation with pediatricians, nurses and general practitioners:

[...] I went to take her to the clinic, there the nurse saw and asked me to take her to the doctor in the morning, so I took her. The doctor looked and said, "Oh, I'm going to make a note to take to the clinic up there that's in the child's clinic" (Dahlia's mother);

I took it to the doctor, in the clinic, the doctor examined and just to see the symptoms said: "these are symptoms of cancer, visible" (Mother of Rosemary).

The identification of the problem culminates in the search for a cause so that appropriate therapy begins. It is verified that the early diagnosis occurred only in one case, in which the mother sought a single service in which the health professional detected, from the signs and symptoms, that the child had cancer:

The day I arrived, it was a Sunday, they (health professionals) picked up and began to ask what he (the child) was feeling. Then I told him that he could not stand, he always complained that he was tired, he slept too much and he was not eating. Then, on Monday, they took blood work, on Tuesday, they told me that he had leukemia (Mother of Narcissus).

In other cases, the child's cancer diagnosis was not immediate, which led to the families' exhaustive pilgrimage, ranging from one to eight public and private services. In the following speeches, the mothers report that the use of the private service occurred because they did not find a solution and did not rely on the care of the professionals in public unity. They also mentioned the absence of a specialist for the care of the child, and it was necessary to seek the professional in another State, and although the latter had made the diagnosis precisely, he did not send for admission to the Unified Health System (UHS):

[...] we took her to the doctor there in Apucarana. [...] He asked for the exams and said like this: "tomorrow we will do the exams again". Then she did it and gave it and he called me and said that she had to come to Londrina (Mother of Violet);

[...] there she thought it was a tumor herself, the doctor there in EMC (Emergency Medical Care). So I did not believe in being in EMC [laughs] (Mother of Hydrangea);

[...] Then the tests were all negative and she had the transfusion and continued with the medication, and that anemia did not improve. Then her pediatrician sent for a hematologist who, in my city, there is none. Then I paid a consultation in the city of Ourinhos, State of São Paulo, with a hematologist, then I got there with all the exams, she looked, asked some more and then, in return, with everything she had in her hands, she said : "Look, Mom, this is leukemia, if I ask for a myelogram for you, it's private here and it's very expensive and I can not treat you, refer you to UHS because you're from another state, you're from Paraná and here is São Paulo, then, back there in your city and ask your pediatrician for a referral to your region. In Jacarezinho, in her pediatrician, he said he could not forward because his care was private, my husband almost hit him, because until then he had been her pediatrician and when she needed it he could not forward it. Then we went to the city of Santo Antônio da Platina (which is another neighboring city), we paid there, everything paid, we paid a private consultation with the doctor, but she also attended the UHS and we passed all the exams, it was already night, there she got it, sent all my daughter's exams by fax to the doctor (COC Londrina). When it was eight o'clock in the evening she called, she said that she could come on Monday that everything would be right already for hospitalization, to do an investigation (Mother of Sunflower).

In the following reports there are moments of insecurity, since the professionals did not identify the cancer and made other diagnoses with the respective treatments, delaying the inherent to the real disease. There were cases in which the mother herself asked the doctors to examine the causes of the child's illness, for, even if she took her child periodically and reported that the child was not well, the clinical conduct was maintained:

[...] Pain on the side of the navel. I thought it was hernia, but it was not, it was a tumor that the doctor said could be a worm (Mother of Rosa);

[...] Because the doctor had already come to talk to me that she (the child) was going to be admitted for treatment of Infantile Rheumatoid Arthritis [...] (Mother of Begonia);

[...] because I took her to the doctor every month, but the doctor had never asked for an exam before [...] nine months, I checked the appointment and I took [...] myself: "Look, doctor, I want a blood count," and then it's a deep anemia. Then he asked for

new tests and said that it could be a genetic disease. [...] (Mother of Sunflower);

[...] I took her to EMC, they hit the plate, then the doctor said: "Ah, she has a tumor, her heart is bigger than it should be." I waited another day, waited to give Monday, I missed the service, went to the child's clinic, interned. Then he sent us to the Infantil (hospital), we stayed one more week in the Infantil and they thought that that cough was tuberculosis [...]. Then he saw that it was nothing like that, he sent it here (COC) (Mother of Hydrangea).

In addition to the worsening of the pilgrimage in the health services for the definition of the diagnosis, the mothers report that some professionals blamed them for the child's illness, not taking into account the trajectory traversed in the services by the families seeking the appropriate treatment for their child. Then, no professional had made the real diagnosis:

[...] Then, arriving at the Children's Clinic, the doctor said: "But then, Mother, this, if something happened, it was your responsibility ... you have to take it, you have to admit it. Then we took him to Providência (hospital of the municipality), he was hospitalized and stayed there for a week. Then they did an ultrasound of the heart, there it was, but they always spoke to me more or less (Mother of Hydrangea);

[...] (Hematologist): "Look, Mother, the disease in children has a great advantage, it has a very good evolution for healing, but only that it evolves very fast, so the longer you take, the more it is putting the life of your daughter at risk (Mother of Sunflower).

♦ The feelings revealed about the diagnosis of cancer

In this sub-theme are expressed the maternal feelings experienced before the confirmation of childhood neoplasia that was characterized as a remarkable moment in the lives of these women who, despite their own suffering, remained strong to help their children.

The discourses are permeated by intense emotional component, described as feelings of revolt, disbelief, despair, fear and experienced as a unique, shocking, painful, traumatic and desperate experience:

At the time I fell [...] there was even a revolt (mother of Sunflower); [...] we were very shocked, we cried a lot (Mother of Violet);[...] it seems that it took the floor, [...] it seems that I did not have the spirit nor to live more. I could not even take care of my service any more [...]. I even forgot about my oldest son. It was very difficult [...] (Mother of Tulipa);

Ah, I was shaken[...] I thought it was a lie, that it was a dream, that I would wake up and it was a nightmare, I did not believe that this was happening to me (Mother of Rosemary).

And, around these feelings, some speeches showed gratitude for the fact that they finished the journey in search of what was previously unknown and would now begin the appropriate treatment. On the other hand, with the confirmation of the disease, stigmas and prejudices appeared, and the disease was seen as synonymous with death:

[...] we did not take care of anything, he (doctor) took care of everything, he (doctor) sent it right here (COC). Oh, thank God, I just have to thank God, the doctors and the nurses [...] (Mother of Violet);

I was shocked, I could not believe that she was with this disease because until then it is a disease that always scared me. It's difficult because we never expect such a disease. You see the neighbor who died, I met people who in six months passed away after they discovered the disease. My grandfather died of this disease, my ex-husband's grandfather died of it, so when you talk about cancer you're going to die. It's an ugly name, it's a heavy name that resembles death. Here comes the doctor and says that your daughter has this disease, it is very difficult, you are shocked (Mother of Lysanthus).

Although some speeches have revealed feelings of suffering before the confirmation of the diagnosis of cancer, in others, it was possible to grasp the hope of healing based on spiritual belief:

[...] But there you create a defense in the body, you create immunity, then God will strengthen you and you will live. [...] I believe as soon as she is healed! (Mother of Lysanthus);

[...] I have faith in God that everything will work out, every day better (Violeta's mother);I hope she heals, that she get's better and that I live my life from before, normal. From before, before even, I do not know if it comes back, but there is only God to give strength. You have to think positive, although you see things wrong [...] (Mother of Hydrangea).

DISCUSSION

The data in this study on childhood cancer indicates that its onset does not differ from the data provided by the National Cancer Institute (INCA), which is a disease difficult to identify due to several factors, including the fact that its clinical presentation occurs through signs and symptoms that are common to diseases in this age group, disfavoring the diagnostic definition of cancer, such as: fever,

vomiting, weight loss, bleeding, generalized adenomegaly, generalized bone pain and pallor.[1]

The confrontation of the disease is permeated by cultural values that influence the understanding and attitudes of the patient. This is nothing more than the way a person positions himself in the face of illness after applying meaning to him based on the experiences, values, and pre-existing interactions with the people who surround him.[8]

The difficulty of identifying cancer, mobilizes the family to look for several services when the first does not promote the treatment of the pathology that was still undefined. In this sense, one of the major mishaps identified is the lack of resolution, since, often, actions that permeate care happen in a disconnected way and postpone the detection of the problem.[5] An aggravating circumstance is the lack of support from the networks support, characterized as helplessness to mothers as far as the financial factor (lodging, transportation, food, purchase of medicines, etc.) and receiving of information.[12]

Considering the importance of early diagnosis for the prognosis of better quality of childhood cancer, it is recognized the need for effective actions that reduce the time from the onset of symptoms to the diagnosis of the disease, especially among children. Therefore, accessibility is a strategy aimed at guaranteeing this effectiveness, starting with primary care, considered as the "gateway" of the individual seeking medical care and will only be referred to the specialist when the solution of their health problem does not reach that level of care.[5]

It is observed in the speeches that the mothers traveled the correct way, that is, they initially sought a primary care service. However, the arrival at the specialized service was delayed, which indicates the fragility in the organization of the health services, which is punctuated as one of the factors that interfere in the early diagnosis of cancer. In addition, resources for cancer treatment are precarious and insufficient to meet the demand that increases each year.[3,5,13]

After the difficulties experienced in the path to the diagnosis, in the maternal reports, the relatives' feelings about the disease were revealed. They are fruits of experiences, some of which disappear and give way to others, while others persist over time, such as fear and hope, directly related to uncertainties.[6,14-5] In addition to the complexity of the disease, denial, sadness, acceptance and confrontation, since there is no other way out but to fight. Parents and/or family members, when feeling responsible for the disease, may lose the rules and change the balance of everyday life. Already the process of early mourning of the child and/or adolescent by the family is commonly observed and she tends to isolate herself and close around herself. [3,14]

The relationship between cancer and death is commonly described in our daily lives and is linked to previous experiences and the fact that for a long time people diagnosed with this disease died quickly. This becomes more evident, arousing nonconformity, when it involves the child, because it has not yet fulfilled the life cycle.[15]

On the other hand, it is evident in the discourses that mothers have acquired motivation over time, based on beliefs that awaken the hope of healing and relief from suffering. "It is important to take into account that responses to the problems created by the disease are socially and directly related to a shared world of practices, beliefs and values." [8: 171] In this context, spiritual interventions such as listening, being present, giving direction have been termed as attentive responses that constitute the foundation for spiritual care in nursing, sustained by an understanding of care that strengthens spirituality.[16-7]

“"For anthropology, disease is not only a 'biological entity', which should be treated as a thing; It is also experience that is constituted and acquires meaning in the course of interactions between individuals, groups and institutions.”.[8:171] In this way, faith and spirituality are points of strength, comfort and hope, [11,16-8] as well as the health institution in which this family is inserted, which has aided in the better acceptance of the chronic condition of the child and adolescent.[16-7]

The care of the child and family requires multiprofessional and interdisciplinary care to meet the needs caused by hospitalization. Thus, it is necessary for health professionals to develop a holistic care providing, among other things, emotional support for these subjects.[19] In this sense, the importance of the nurse professional is highlighted, since it is inserted in the different phases of care, since prevention, even the treatment of the child with cancer, exercising its assistance and managerial role in a reality that demands integral attention, with emphasis on the essentiality of the creation of bonds.[20]

CONCLUSION

In the child with cancer, the family course until diagnosis was variable, depending, among other factors, on the diagnostic capacity of health professionals. Living with the mothers and children with cancer revealed a world of suffering and uncertainties in the path traveled, from the moment of the first signs and symptoms up to the diagnosis.

The experience of the disease was not observed in a linear way, and each family, despite the similar diagnosis, has different ways of perceiving and facing childhood cancer. The moment of communication of the diagnosis is lived under a climate of vulnerability and confrontation with reality, later added insecurity and fear of death, which appear entangled with hope for healing and faith in the course of treatment. This promoted a more comprehensive understanding by the nurse about the difficulties and strengths that permeate the whole process, that is, it was possible to understand, through the reports, the experience and the confrontation of the disease experienced by these subjects.

Therefore, the need for clear, effective, welcoming and empathetic communication, that is, that there is a therapeutic relationship between family and health team, is highlighted. It is also important to qualify and improve health policies so that the diagnosis of cancer is precocious, since suffering and distress can be mitigated by the rapid onset of treatment.

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